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Non-participation in screening: The case of cervical cancer in Denmark

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ABSTRACT

Objective. To determine the impact of comprehensiveness of cytology registration on the proportion of cervical cancer patients without a recent screening history.

Methods. For Danish women diagnosed with cervical cancer in 2003–2007, we used cytology data from the nationwide Danish Pathology Data Bank and the National Health Service Register. In five steps, we included data from an increasing number of cervical screening laboratories into the analysis, and calculated the proportions of screened women who had cytology registered in two screening rounds prior to the cancer diagnosis.

Results. In total, 1867 cervical cancer patients were included in the analysis. When looking only at the screening history in the laboratory that diagnosed the cancer, it appeared that only 40% of women were screened in the last two rounds. This proportion increased to 55% when nationwide screening data were used. This corresponded to a 25% decrease in the proportion of patients without a recent screening history.

Conclusion. The level of comprehensiveness of screening data makes a measurable difference when evaluating the screening histories of women with cervical cancer. It is important that actions for the improvement of a screening program are based on comprehensive cytology registrations.

Introduction

The burden of cervical cancer has decreased in parallel with the introduction of cervical screening. Screening histories of cervical cancer patients have been used to identify priorities for further improvements. Negative cytology shortly before the diagnosis of cancer may signal low sensitivity of the test. Recent abnormal tests may signal inadequate follow-up. No recent test may signal failure to reach high-risk women.

Non-attendance is known to be a major problem. In a meta-analysis (Spence et al., 2007), 53.8% of cervical cancer patients were estimated to have a "deficient screening history". The studies differed in terms of e.g. length of analyzed screening history and stage of disease. Furthermore, screening data sources varied from hospital (Brinkmann et al., 2005; Womack and Warren, 1998), to regional (Jansson et al., 1998), or national registration (Andrae et al., 2008; Bos et al., 2006). The studies might therefore vary in data comprehensiveness, an aspect so far given limited attention. The problem with data sources restricted to a local laboratory registration is that they may miss relevant data, e.g. owing to women changing their address. Therefore, the number of patients screened might be underestimated when "local" registration only is used, and may consequently inadvertently shift the priorities for improvement.

While screening histories of Danish women with cervical cancer have been investigated previously (Ingemann-Hansen et al., 2008; Kirschner et al., 2011), the aim of our study was to describe the changes in the proportion of cervical cancer patients without a recent screening history when we varied the number of laboratories included in the analysis. This study was facilitated by the existence of highly complete Danish population-based health care registers.

Methods

Cervical screening in Denmark

Mass cervical screening in Denmark started in the 1960's. National guidelines from 1986 recommended integration of the existing organized and opportunistic activities with personal invitations every third year to women aged 23–59; a policy gradually implemented in all of Denmark. Since 2007, screening has been recommended every third year for women aged 23–50, and every fifth year for women aged 50–65 (Anttila and Ronco, 2009). In 2010, the three-year coverage was about 76% (Styregruppen for DKLS, 2011).

Data sources

Data on cervical cancers diagnosed from 1 January 2003 to 31 December 2007 were retrieved from the nationwide Danish Cancer Register (DCR)

Abbreviations: CPR, Danish Personal Identification Number; CRS, Civil Registration System; DCR, Danish Cancer Register; ICD, International Classification of Diseases; NHSR, National Health Service Register; NOS, Not Otherwise Specified; Patobank, National Danish Pathology Data Bank; SNOMED, Systematized Nomenclature of Medicine.

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(Gjerstorff, 2011). Six extra patients were added to the study following an expert pathologist (BB) review of the free texts of biopsy reports (Appendix A). Information on the stage of invasion could not be retrieved from this register.

The Danish National Pathology Data Bank (Patobank), the national histopathology and cytopathology register was established in 1978 and gradually became nationwide (Bjerregaard and Larsen, 2011). We retrieved information on all cytologies and histologies with topography codes of cervix uteri, vulva, vagina and uterus not otherwise specified (NOS; Appendix A).

The National Health Service Register (NHSR) includes payments in primary health care from 1990 onwards (Sahl Andersen et al., 2011). No payment is made unless a registration has been processed. We retrieved all registrations on cervical cytologies (Appendix A). The registration of cervical cytologies in the Patobank and in the NHSR may result in double entries, and this is illustrated in Table 1.

The Danish Civil Registration System (CRS), established in 1968, contains information on all individuals with a permanent address in Denmark (Pedersen, 2011). We retrieved the information on the women's dates of birth, residency status and residency area. Each individual receives a unique personal identification number (CPR-number). CPR-numbers were used for linkage of the four registers. Data were retrieved until 31 December 2007.

Definitions

Diagnosing laboratory

The data retrieved from the DCR did not include information on the diagnosing laboratory. We defined the diagnosing laboratory as the laboratory with the first Patobank cervical cancer record in ±1 year of the year of the DCR diagnosis. In Denmark, cancer diagnoses are rarely made by private pathologists only.

Screening history

For each patient we retrieved data on cervical cytologies in the Patobank and the NHSR. To avoid double-counting, we followed a protocol. Firstly, within the NHSR, a payment for the same cytology specimen can be claimed by both the cytology-taker and the cytology-reader; if less than two months apart, we considered only the first. Secondly, in both the NHSR and in the Patobank, a woman may have more than one cytology registered on the same day, which we counted only once. Finally, if a woman had both a cytology in the NHSR and in the Patobank in ±1 month, we counted only the first one.

It was not possible to determine whether cytologies were taken as part of a screening or a diagnosing process. We assumed that cytologies taken less than six months before the diagnosis were obtained as part of the diagnosing process, and excluded them from the analysis. We calculated the percentage of women screened within more than six months and less than four years, and within more than four years and less than 7.5 years before the diagnosis. In Denmark, the former period corresponds to approximately one screening interval before the diagnosis, allowing for a delay of six months. The latter period corresponds to the last-but-one screening interval.

County of cervical cytology reading

In Denmark, cytology samples are sent to the laboratories in the county where the woman lives. By 1 July 1995, the first date for evaluation of screening history in the present analysis, the Patobank included virtually all (defined as ≥85%) cervical cytologies from 14 out of the 16 counties. For cervical cytologies registered only in the NHSR, we assumed that the laboratory was placed in the county where the woman lived.

Statistical analyses

We studied all cervical cancers diagnosed in 2003–2007 among women with a permanent address in Denmark at the date of diagnosis in five steps. In these steps, we included an increasing number of cervical cytology-reading laboratories as follows:

1. Step1: we examined each woman's screening history registered in the Patobank restricted to the hospital pathology laboratory or the private pathologist where the cancer was diagnosed.
2. Step2: adding to step1 all other laboratories in the Patobank from the county where the cancer was diagnosed.
3. Step3: adding to step2 those cervical cytologies for the same county which were registered only in the NHSR.
4. Step4: we examined all cervical cytologies available in the national Patobank, regardless of the county in which the woman was diagnosed with cervical cancer.
5. Step5: adding to step4 all cervical cytologies which were registered in the NHSR only. This level corresponded to nationwide, i.e. complete, registration of cytology.

Results

Study population

In total, 1990 cervical cancers were diagnosed in 2003–2007. Among these, 1867 (93.8%) could be linked to a diagnosing laboratory, and 123 patients (6.2%) did not match with any laboratory. The number of cancers by hospital laboratory varied from 10 to 182 (median: 85). Average age of patients was 51.3 years (range: 15–99). The number of retrieved cancers, 1990 (October 2009), was similar to the number reported in NordCan, 1961 in June 2011 (Engholm et al., 2011).

Overview of the results

At step1, using only screening data from the laboratories that diagnosed the cervical cancers, 60% of patients had no cervical cytology registered in the last two screening rounds preceding the diagnosis, 9% had a cervical cytology registered only in the last-but-one screening round preceding the cancer diagnosis, and 31% had a cervical cytology in the last screening round before the diagnosis (Table 2). At step5, using national Patobank and NHSR data, 45% of patients had no screening history in the last two screening rounds, and 57% had none in the last screening round.

Effect of data completeness

Comparing step2 to step3 and step4 to step5 allowed us to measure the effect of the completeness of registration. In the analysis restricted to the counties and with data from the Patobank only (step2),

Table 1

Registration of cervical cytology in the National Danish Pathology Data Bank and in the Danish National Health Service Register since 1990.

Cervical cytology read by	Cervical cytology taken by		
	Hospital ward	Private gynaecologist	General practitioner
Hospital pathology department	None in the NHSR, and virtually all in the Patobank[a]	All in the NHSR, and virtually all in the Patobank[a]	All in the NHSR, and virtually all in the Patobank[a]
Private pathologist	Not relevant	All in NHSR,[b] and few in Patobank	All in NHSR,[b] and few in Patobank

Patobank = National Danish Pathology Data Bank. NHSR = National Health Service Register.

[a] The proportion of cervical cytologies registered in the Patobank varied by former county. It was "complete", defined as ≥85% of all cervical cytologies including the NHSR, for 14 out of 16 counties since 1 July 1995, the first date for evaluation of screening history in the present analysis. For one county the Patobank data became "complete" in 2001 and for the last county in 2006.

[b] These cervical cytologies will be registered twice in the NHSR, as payment is registered both for the cytology taking and for the cytology reading.